DOCUMENT RESUME

ED 278 938 CG 019 718

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TITLE A Study of a Home Health Care Program for Low Income Frail Elderly.
PUB DATE May 86
NOTE 45p.; Paper presented at the Annual Scientific Meeting of the Gerontological Society (39th, Chicago, IL, November 19-23, 1986).
PUB TYPE Reports - Research/Technical (143)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Community Services; Cost Effectiveness; Daily Living Skills; Deinstitutionalization (of Disabled); Health Needs; *Health Services; *Home Programs; *Older Adults; Self Care Skills; *Social Support Groups; *Visiting Homemakers
IDENTIFIERS *Frail Elderly; Long Term Care

ABSTRACT

As the number of chronically ill elderly increases and the costs of hospital and nursing home care rises, consideration is being given to alternatives for long-term care. One alternative being explored in California is the Alameda County Homemaker Program which provides home health care to the frail elderly. Interviews were conducted with all 30 impaired elderly clients who received from 2 to 6 hours of personal and household assistance per week. An Activities of Daily Living and Instrumental Activities of Daily Living scale was used to determine the extent of the respondents' impairment and how their needs were met. The results revealed that those elderly who lived alone, had the fewest informal supports, and were being maintained by formal supports were the least impaired of the group. This finding negated the hypothesis that a positive relationship exists between level of impairment and reliance on formal supports. It appears that, beyond a certain level of impairment, formal supports alone are not sufficient to keep the frail elderly at home; formal supports supplement and sustain rather than supplant informal supports. This study suggests that severely impaired elderly may be maintained in the community with minimum home and health care services. Government policies supporting institutional rather than home care must be addressed. (Sixteen data tables are included, and instruction sheets for home care services and forms for determining types of social services needed are appended. (NB)

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A STUDY OF A HOME HEALTH CARE PROGRAM FOR LOW INCOME FRAIL ELDERLY

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May, 1986

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HOME HEALTH CARE FOR LOW INCOME FRAIL ELDERLY

ABSTRACT

This study describes and advocates for the provision of a County sponsored home health care program for frail elderly who do not qualify for MediCal. The necessity for bolstering both informal and formal supports is documented. Client chracteristics, components of the program and cost effectiveness are discussed.

Personal and household assistance is provided from 2 to 6 hours per week to 30 impaired elderly, with an equal number on the waiting list. Each of the care recipients was personally interviewed. Data were gathered on a 7 item Activities of Daily Living (ADL) and an 8 item Instrumental Activities of Daily Living (IADL) scale. Particular attention was paid to availability of informal social supports and their role in the provision of care.

Results describe client characteristics, document which services meet the highest needs, and who provides them. A relationship is established between the provision of formal and informal supports and level of impairment.

Severely impaired elderly may be maintained in the community with the addition of minimum home and health care to the benefit of both the individual and society. Current government policies which support institutional rather than home care must be addressed.

"I'd rather stay and grow old than die young and beautiful..."

INTRODUCTION

This study describes and advocates for the continuation and expansion of the Alameda County Homemaker Program which provides home health care to frail low income elderly. With the growing number of chronically ill elderly and the rising costs of hospital and nursing home care, increased consideration is being given to alternatives for establishing long-term care services. Information is needed on the role of informal support networks in providing long-term care assistance for the elderly in order to develop public policy that will complement and support this role rather than displace it. [1] It is now widely recognized that informal care is the predominant source of care for the impaired elderly. What is emerging is the recognition that the provision of formal supports is an important ingredient in sustaining informal support.

This research establishes who provides supports, what is the nature of the assistance provided, what is the relationship between a person's level of impairment and his/her support network and what is the balance between the supply of informal and formal services, for a given population of impaired elderly in Alameda County. Personal care and household help is provided to clients who are in the greatest social and economic need, that is, lower income elderly who, without the service would require institutionalization or burden family caregivers beyond their physical and mental capacity. A grant from the Area Agency on Aging funds the services. Client characteristics, components of the program and cost effectiveness will be discussed. The necessity for bolstering both informal and formal supports is documented.

RATIONALE

DEMOGRAPHICS

The proportion of the population aged 65 and over is growing dramatically. Between now and the year 2020 the number of older Americans will rise from 25 million to 55 million, or from 11% to 17% of the population. In 1980 the number of persons in Alameda County aged 65+ was 114,601, representing 10.3% of the total population. By 2000 the percentage of elderly in the County aged 65+ is projected to increase to 12.1% of the population. On a national level, while the aged represented 11% of the population in 1980, they accounted for 31% of personal health expenditures.[2]

More significant, given the relationship between advanced age and increased dependency, is the projection that the number of Americans over the age of 85 will more than triple by the year 2020. Because of the rising numbers of the very old, the magnitude and complexity of providing care for the aged will only increase.

HEALTH PROFILE OF THE AGED

Sooner or later each older person will probably face a period of incapacity. Some 80% or more of the population will have one or more chronic diseases or disabilities by the age of 65, some 25-30% will have some signs and symptoms of artherosclerotic cardiovascular disease and almost as many will have some evidence of 'dementia' or 'depression.'[3] As the demographic data indicate, the numbers of persons 75+ will increase most rapidly and they are the ones who are most vulnerable to the physical, mental and social assaults that result in the need for care and services. As acute disease has been controlled and death postponed, chronic illness has emerged as the dominant cause of illness and disability. The unmet need for chronic and long-term care for the elderly is growing rapidly.

Family involvement is a crucial element for avoiding or postponing institutionalization of the impaired elder. Services are sorely needed to supplement and strengthen the family caregiver's capacity to care for the functionally impaired in the community. Witness the plight of

one Alameda case, a 77 year old man with limited mobility, caring for his 75 year old wife. "She often gets up wet and it's all I can do to put clothes on her." Home health care is provided three mornings a week for two hours each. "I need help the other two days. I think I can manage to get by on Saturdays and Sundays by myself."

COST

Although twice as many housebound persons (10% of the elderly) live at home as in nursing homes, a meager 1% of the health care budget is devoted to in-home services, ten times less than what is spent for nursing homes.[4] Despite large numbers of impaired people (estimated at 25 - 30% of the elderly, or 8 million individuals with an average age of 75), who would benefit from home care, more than 90% of public expenditures for long-term care goes to institutions.[5]

A recent report to the State legislature[6] cited savings of approximately $325,000 in State and Federal Medicaid funds over the past two years since waivers were instituted for the provision of home and community-based services to the frail elderly. Since this program is directly administered by the Multipurpose Senior Services Program (MSSP) within the California Department of Aging, participants must be eligible for MediCal. Currently 4000 unduplicated clients in the State of California are being served. One can only contemplate the potential savings to individuals and society if subsidized in-home services were readily available to all financially needy segments of the older population who are in danger of institutionalization.

RECENT FINDINGS

It is becoming well documented in the literature that older persons with few or limited family relationships are prime candidates for institutionalization when they become sick.[7] Shanas has estimated that 5 - 10% of all noninstitutionalized older persons require some home care and that about 80% of this home care is provided by family and friends. Two issues raised in the literature for which additional data is said to be needed, are how much do elders rely on informal sources of assistance and for what kinds of activities do elders use informal

assistance.[8] It is acknowledged that an understanding of the operation of informal helping networks will assist practitioners in identifying unmet needs of the clients they serve and is a prerequisite for designing formal home care programs which complement rather than duplicate those services provided by informal helpers.[9]

One of the continuing concerns in the literature on the elderly has been the nature of their social supports. Social support networks may be defined as "that set of personal contacts through which the individual maintains his social identity and receives emotional support, material aid, services, information and new social contacts."[10] With the loss of family members and friends which is experienced with declining age, the elderly lose important bases for social integration. These losses are repeatedly lamented. "Everyone I know recently died. The older I get the faster they are dropping off." "I get grieved - my mother died, my husband is gone, my son was next. I'll stay here with God." At the same time, with the problems of declining health, increased confinement to home, and limited ability to meet one's own needs, greater need for social support is created. Social support represents more than simply the quantity of social ties such as numbers, frequency, proximity, but rather support resides in the actual fulfillment of needs through the provision of help.[11] What interests researchers is the role played by informal social supports in relation to formal care.

In a study conducted by Stoller[12] a four category index of the composition of an elder's helping network was created to reflect the mix of formal and informal sources of assistance.

1. An empty network (no helpers).
2. An informal network in which all helpers were family, friends or neighbors.
3. A formal network in which all helpers named were formal service providers or hired help.
4. A mixed network composed of both formal and informal helpers.

This study examines components of the latter two categories, with particular emphasis on the mixed networks combination of formal and informal helpers. Data is accumulating which suggests that formal

services alone do not provide sufficient care and that informal and formal services are complementary.[13]

HYPOTHESIS

There is a positive relationship between a person's level of impairment and his/her reliance on formal supports. It would be expected that severely impaired elders do need and use more formal support than do less impaired elderly. Persons with high informal support networks are expected to be less impaired than are persons with low informal support networks. It is anticipated that as a person's functional level diminishes with the decrements of aging, the burden of care increases so that informal sources of support withdraw or collapse.

COMPONENTS OF THE PROGRAM

The Alameda County Homemakers Program operates with an annual grant[14] of $35,000, serving 30 clients throughout the County who do not qualify for MediCal but who have low income. The program is administered by Family Counseling & Community Services, a private non-profit agency, and offers clients from 2 to 6 hours of service per week at no cost to them. Eligible participants are over the age of 60, do not qualify for SSI, but lack sufficient funds to pay for services. The guidelines are an income of no more than $800 per month per person, or $1510 per month per couple. To help subsidize the program, donations are requested on a bi-monthly basis, specifying that service provision is in no way related to whether or not a client can or will contribute. In-home care is generally provided in 2 hour periods, twice or three times a week. In some cases 3 hours of service are provided twice a week.

A care plan (Appendix A) is designed by a registered nurse who makes an initial home visit at the time the program has an opening. A waiting list is kept and prioritized. Openings become available as clients move away, are hospitalized for more than 2 weeks, are institutionalized, or die. The level of impairment is such that a review of past records reveals no cases of services terminating due to a client's

improved condition. In some cases the number of hours may be decreased. At intake a person's needs are assessed, a care plan is determined, and a home health care worker is assigned. The range of services offered consists of personal care, housekeeping, activity assistance, shopping, meal preparation and companionship. Personal care is described as "hands on" bodily care such as bathing, washing, shampooing hair, changing clothes. Housekeeping is light housekeeping such as doing dishes, cleaning the kitchen, cleaning the bathroom, mopping floors, vacuuming, changing bed linens and doing laundry. Activity assistance includes such things as toileting, transferring in and out of bed and helping with exercises. Although 'companionship' is included in the care plan, this role was not found recorded on any charts as a task performed.

The personnel administering such care are usually certified nurses aides or aides with years of experience who are not certified. Homemakers who do no "hands on" care need not be certified. All workers are supervised and monthly contact is supposed to be maintained with the client by the worker's field supervisor. According to self-reports by clients, only 3 of the 30 receive only homemaker services. More commonly the hours are equally divided between personal care and homemaker tasks.

METHOD

All 30 clients who receive homemaker/home health care services under the Alameda County Homemaker Program were personally interviewed over a one month period. An open ended interview format was used. (Appendix B). The average interview time took 30 minutes and was conducted in the subject's place of residence. In the 5 cases where the subject was cognitively impaired the family caregiver was the respondent. It was decided to include these cases rather than lose data on how those who are too impaired to be interviewed remain in the community. Thus the sample equals the total number of clients in the program at the time that data was being gathered.

One of the concerns raised in the literature is that most data gathered about assistance to the elderly rely solely on self-reports which can lead to distorted conclusions.[15] Taking this into consideration client records were examined at the offices of the Home Health Care agency from which home health aide workers originate. Care plans and

services provided were verified with the subjects' reports of services needed and received. First hand data from informal supports, however, was not gathered, except in those aforementioned cases where the care-giver served as respondent. Client satisfaction was also recorded during the interview and these results, along with the subjects' awareness of the availability of other community resources are reported elsewhere.

ANALYSIS

To test the hypothesis and establish a relationship between level of impairment and provision of supports, each task requiring help, "who washes the face and who washes the floor,"[16] was examined according to whether assistance was provided by an informal or formal support system. "Informal support network" is defined as an elder's spouse, living children, siblings, other relatives, friends and neighbors, - those "significant others" with whom the elder has close contact,[17] as measured by services provided, frequency of visits and telephone calls. Informal care may be described as being provided out of love, duty, necessity or compassion. The "formal support system" of which we speak refers to the governmental and voluntary service agencies and the health and other service professions who stand ready to provide long-term care services to elderly living in the community, that is, formally organized services.[18] In this program such services are provided under the supervision of a private Home Health Care Agency, overseen by the Family Counseling & Community Services Agency and funded by the Alameda County Area Agency on Aging.

The source of informal support was noted according to the relationship between the provider of care and the elder, that is, support provided by a spouse, family member, or friend. Social support in terms of number and frequency of weekly contacts, the availability of a confidante, and the existence of an emergency contact person was also recorded for each subject.

INSTRUMENT DESIGN

In order to determine the extent of a client's impairment and how his/her needs are met, a 15 item Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) scale which included social supports was used. (Appendix C). This scale was designed not only to measure the subject's level of dependence, but also to ascertain the specifics of assistance provided by informal and formal supports. The ADL scale is one of the most commonly used and carefully studied tests which measures dependency in 7 functions. "Basic" ADL describes such activities as walking, dressing, eating, bathing and grooming. The IADL measures the ability to perform 8 activities required of independent living in the community. "Instrumental" activities refer, for example, to housekeeping, transportation, food preparation, grocery shopping and personal business affairs.[19]

RESULTS

CLIENT CHARACTERISTICS - DEMOGRAPHIC DATA

A profile of the 30 clients served by the Alameda County Homemaker Program indicates that one half of the population is under the age of 75, and one half is over 75, with an age range from 62 to 88. Of these, 11 are Black and 19 are Caucasian. As could be expected with this age group, women predominate, with 25 women and 5 men receiving services. Sixteen of the subjects live alone, 10 live with a spouse (each of the 5 men lives with a spouse), two live with a daughter, one lives with a sibling, and one lives with his former wife (for economic reasons). A review of marital status shows that 13 are widowed, 10 are married, 3 have never married, and 2 were divorced. With regard to family status, 13 reported having no living children, another 13 had more than 2 living children and 4 persons had an only child. Of those 17 with offspring, 15 had a son or daughter in the same city, one other had a child in the Bay Area and one's child lived outside the area. Table 1 summarizes the demographic characteristics of the population.

TABLE 1

Demographic Characteristics of Clients

n = 30

		n	%
Sex:	Female	25	83%
	Male	5	17%
Ethnicity:	Black	11	37%
	Caucasian	19	63%
Age:	60 - 69	6	20%
	70 - 79	16	53%
	80+	8	27%
Total population Under 75 (the 'young old')		15	50%
Total population over 75 (the 'old old')		15	50%
Marital Status:	Widowed	13	43%
	Married	10	33%
	Never Married	3	10%
	Divorced	4	14%
Household Composition:			
	Alone	16	53%
	With Spouse	10	33%
	With Offspring	2	7%
	Other	2	7%
Of Those 16 Living Alone:			
	Under 75 years of age	6	20%
	Over 75 years of age	10	33%
Family Status:			
	No living children	13	43%
	More than 1 child	13	43%
	1 child	4	14%
Of Those 17 with Children, Proximity of children:			
	Same City	15	50%
	Bay Area	1	3%
	Outside Bay Area	1	3%

FUNCTIONAL STATUS OF CLIENTS

By virtue of their inclusion in this population, none of the subjects is in good health. There is, however, quite a variation in both physical and mental status. Two clients are blind, 2 are bedridden, 5 are confined to a wheelchair and 4 use oxegyn to aid respiration. Five of the clients are cognitively impaired. Six had only the ability to eat independently. The population has very limited mobility, with only 3 (10%) having independent ability to leave their place of residence. Eighteen, or 60%, report leaving home rarely, only for a medical appointment, or never. Five, or 17%, do go places with the assistance of someone else, and 4, or 14%, attend social day care or adult day health care centers on a regular basis with the use of a paratransit service. An interesting aside is that only 16 (53%) of the 30 subjects routinely get dressed, the other 14 remaining in nightwear at all times. Table 2 summarizes the extent of physical and mental limitations among this population.

Table 2

Physical and Mental Limitations of Population

	n	% of total population
Blind	2	7%
Bedridden	2	7%
Wheelchair confined	5	17%
Need Oxegyn	4	14%
Cognitively Impaired	5	17%

LEVEL OF DEPENDENCE

Table 3 provides a synopsis of the population's ability for self maintenance on a combined scale of 15 activities of daily living and instrumental activities of daily living.

Table 3

Percent of Clients with Ability to Function on 15 item Basic Activities of Daily Living

n = 30

	1 Manage Indep-endtly	2 Manage with Assistance	3 Unable to Manage
Telephone Use	70%	20%	10%
Ambulation at Home	37%	43%	20%
Ambulation within walking distance	20%	27%	53%
Shopping for groceries/clothes	3%	17%	80%
Meal Preparation	23%	20%	57%
Housework	0%	13%	87%
Medications	60%	20%	20%
Money Management	40%	13%	47%
Eating	93%	7%	0%
Dressing	43%	27%	30%
Hygiene & Appearance (Maintain)	33%	37%	30%
Bathing/Showering	10%	37%	53%
Transfer in/out bed	70%	13%	17%
Toileting	63%	20%	17%
Transportation	13%	0%	87%

For purposes of analysis a measure of a subject's level of impairment was designed based on the extent of his/her dependence on others for carrying out these basic activities of daily living. A score of 1 was assigned for each activity which could be performed independently, 2 for each activity which required assistance, and 3 for each activity which the subject was unable to perform. Thus the minimum aggregate score would be 15, for independence in performing all tasks, and the maximum score for total dependence would be 45. The cumulative scores for this population of 30 frail elderly ranged from a low of 18 to a high of 41, with a mean score of 30.

In order to study the extent of the services provided by formal and informal systems, in relation to subject's level of impairment, the subjects were divided into 3 groups. Group I refers to those who were the least impaired of the population, Group II includes those who had moderate impairment compared with the others, and Group III designates those who were the most impaired of all. The terms "least", "moderate",

and "most" are used figuratively for this population, since by inclusion each subject has significant enough impairment that he/she is unable to function independently in the community. Such categorization is strictly for purposes of analysis. Assignment to each group was based on a person's composite score for all 15 activities. Thus, those considered to be 'least impaired', of which there were 7, had a score between 18 and 25. Those 10 with 'moderate impairment' had a score between 26 and 30, and the 13 considered to be the 'most impaired' had a score of over 30.

Table 4

Extent of Impairment in the Population

n = 30

	n	%
Group I - 'Least Impaired' (ADL/IADL Score 18 - 25)	7	23%
Group II - 'Moderate Impairment' (ADL/IADL Score 26 - 30)	10	33%
Group III - 'Most Impaired' (ADL/IADL Score 31+)	13	43%

AVAILABILITY OF SOCIAL SUPPORTS

A summary of the availability of family supports, as reported in the demographic data is presented in Table 5.

Table 5

Availability of Family Supports

n = 30

	n	%
Spouse only	3	10%
Spouse & living children within one hour drive	7	23%
Living children only, within one hour drive	9	30%
Sibling only	1	3%
Former wife only	1	3%
No Family	9	30%

To further establish the availability of an informal support network respondents were asked if they had a confidante, that is, someone with whom they could talk about their feelings or in whom they could confide. Of the total population 5 are cognitively impaired, 9 expressed that they had no confidante, 9 reported that a friend was their confidante, 5 named their spouse, and 2 others reported their sibling and child, respectively.

Table 6

Presence of Confidante

n = 30

	n	%
Impaired	5	7%
No confidante	9	30%
Friend	9	30%
Spouse	5	17%
Child	1	3%
Sibling	1	3%

An additional probe for ascertaining the availability of social support was to ask the subject who he/she would name to be contacted in the event of an emergency. Responses to this question revealed that 12 people would have a child contacted, 6 named their spouse, 4 specified some other relative, 5 would count on a friend or neighbor, and 8 mentioned only a formal support such as his/her Doctor or calling 911.

Table 7

Emergency Contact

n = 30

	n	%
Child	12	40%
Spouse	6	20%
Friend/Neighbor	5	17%
Other relative	4	14%
Formal	3	10%

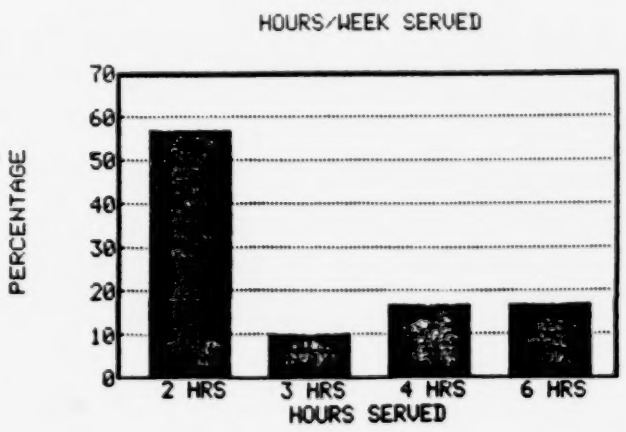
As previously stated, social support emanates not only from the provision of material aid and services, but also from emotional support and social contact. In order to develop a more comprehensive measure of the social support network of this group of 30 frail elderly, further responses were elicited regarding their frequency of telephone calls and visits. A measure was taken of the number of people with whom each subject was in contact and the weekly number of telephone calls and visits received. The number of persons each subject was habitually in touch with ranged from 1 to 11, with the average being 3.5. Telephone calls and visits were tabulated according to whether they were daily, more than once a week, once a week, or less than once a week. Greater weight was assigned to visits than to telephone calls. For each person a support network score was computed based on the number of people he/she reported seeing during the week, the frequency of visits and telephone calls, the presence of a confidante, and the availability of an emergency contact.

PROVISION OF FORMAL SUPPORT

Having ascertained the demographic characteristics, the functional capacity of the population, their level of dependence and availability of informal supports, let us examine the extent of their reliance on the formal support system provided through the Alameda County Homemakers Program.

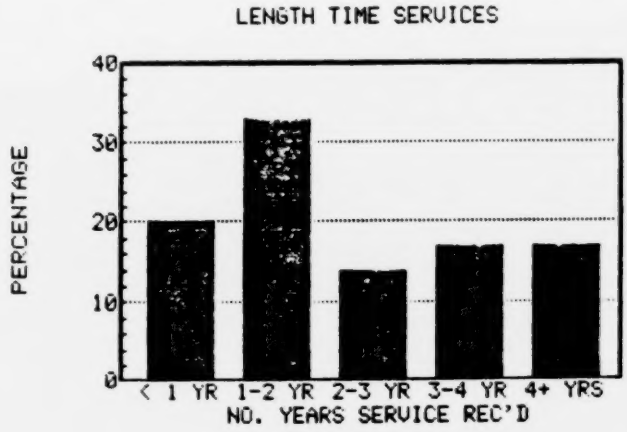
Of the clients presently being served, 17 receive 2 hours of service a week, 3 receive 3 hours of service, 5 have 4 hours of service each and 5 get 6 hours of service per week.

Figure 1



The average length of time that service is maintained is 24 months, with the most recent client added 6 weeks prior to the study and the longest served client having been attended to for over 4 years. Six clients were added during the past year, 10 clients have been served between 1 and 2 years, 4 from 2 to 3 years, 5 from 3to 4 years and 5 for more than 4 years.

Figure 2



ALLOCATION OF FORMAL SERVICE

Given this information the assumption might be made that those clients requiring the most hours of service per week would be the most impaired. In fact, there is almost an equal number of most impaired clients receiving 2 hours per week as there are receiving 6 hours per week. The critical variable is the availability of an informal support network. Table 8 indicates the allocation of hours per week amongst the total population, their age, sex, ethnicity, household composition, level of impairment and the group to which they are assigned for analysis (Group I, II or III).

Table 8

Formal Support by Hours

Hours of Service/Week	Age	Sex	Ethnicity	Household Composition	Total ADL/ IADL Score	Group Assignment
2 hrs/wk	76	F	Caucasian	alone	17	I
57%	86	F	Caucasian	alone	18	I
	79	F	Caucasian	alone	20	I
	88	F	Caucasian	alone	21	I
	67	M	Caucasian	ex-wife	22	I
	79	F	Caucasian	alone	23	I
	74	F	Caucasian	alone	26	II
	87	F	Black	alone	27	II
	73	F	Caucasian	alone	28	II
	71	F	Caucasian	w. sibling	28	II
	65	F	Black	alone	29	II
	80	F	Caucasian	w. daughter	32	III *
	74	M	Caucasian	w. spouse	34	III *
	68	F	Black	alone	37	III *
	74	F	Black	w. daughter	38	III *
	63	F	Caucasian	w. spouse	39	III *
	72	M	Black	w. spouse	40	III *
3 hrs/wk						
10%	62	F	Black	alone	21	I
	79	F	Caucasian	alone	28	II
	73	F	Black	alone	30	II
4 hrs/wk						
17%	87	F	Caucasian	alone	26	II
	77	F	Caucasian	alone	29	II
	76	M	Black	w. spouse	34	III *
	70	F	Caucasian	w. spouse	34	III *
	83	F	Caucasian	w. spouse	38	III *
6 hrs/wk						
17%	81	F	Black	alone	28	II
	75	F	Black	w. spouse	38	III *
	80	F	Caucasian	w. spouse	40	III *
	71	M	Caucasian	w. spouse	41	III *
	68	F	Black	w. spouse	41	III *

* Most severely impaired n = 13

COMPARISON OF FORMAL AND INFORMAL SUPPORT SERVICES

Having documented the dependency needs of the population (Table 3), and the allocation of hours/week provided by formal supports (Table 8), let us examine the nature and frequency of all sources of assistance provided to them. Table 9 summarizes the frequency and kinds of assistance provided by informal and formal supports, as reported by the 30 subjects.

Table 9

Frequency of Services Provided by Various Sources

n = 30

Assistance With:	Spouse	Family	Friend	Home Health Aide	Social Services
Ambulation in					
Walking distance	3%	7%			
Shopping	37%	30%	20%	33%	
Meal Preparation	37%	17%	3%	17%	26% (Meals on Wheels
Housework	23%	10%		93%	Sr. Housing)
Medications	27%	7%			
Money Management	30%	23%	7%		
Eating	3%				
Dressing	23%	10%	7%	27%	
Hygiene/Appearance	10%	3%	3%	63%	
Bathing/Showering	10%			83%	
Transfer in/our bed	7%	3%		3%	
Toileting	10%			3%	
Transportation	13%	23%	10%		23% (Paratransit)

Twenty-five subjects (83%) receive services from both formal and informal sources. Assistance may be divided into two categories, that is, assistance in the performance of Activities of Daily Living (ADL), and assistance in the performance of the Instrumental Activities of Daily Living (IADL). A comparison of the frequency of ADL and IADL tasks performed by spouses, family, friends, and formal support services is depicted in Figures 3 and 4.

Figure 3

Assistance Provided with ADL

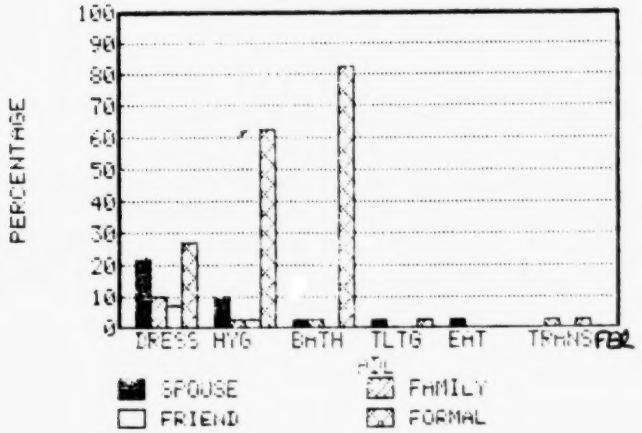
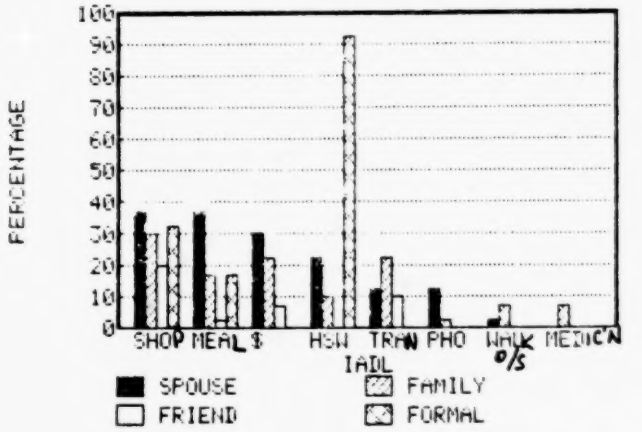


Figure 4

Assistance Provided with IADL



The greatest need for the provision of care is in the area of housework and often it is simply the maintenance of a clean living environment which is enough to help keep a person in his/her own surroundings. Bathing and maintaining personal hygiene are also high on the list of services required by formal support services. Outside of a spouse, who is often hindered by his/her own physical limitations, there is no one else who can acceptably provide this assistance. Overall, each client needs some assistance in both personal care and housekeeping services.

Having reviewed the sources for provision of aid, note is taken of which tasks are not performed by the various helpers, according to the respondents. (Assistance with ambulation is not included since this assistance generally refers to the use of assistive devices such as a cane, walker or crutches). Home health aides do not assist with telephone use, medications, money management, eating or transportation. Friends do not assist with telephone use, housework, medications, eating, bathing/showering, transfer in/out of bed, or toileting. And, finally, there is nothing that spouses do not do! "I'm getting punchy from caring for him. I empty bedpans, bathe him, dress and undress him, cook meals and give medicine. I get up and give him medications every four hours during the night."

FORMAL SUPPORT ONLY

Only 5 subjects (17%), all of whom are women and all of whom live alone, reported having no informal supports available. It is interesting to note characteristics of those who are totally dependent upon the provision of formal supports in order to maintain their ability to function in the community. Table 10 summarizes these 5 clients.

Table 10

Characteristics of Clients With No Informal Supports

Age	Ethnicity	Marital Status	No. Living Children	Impairment level (by Group)	Hrs/Wk Service Received	No. Tasks Need Help With
74	Caucasian	Widowed	2	II	2	5
76	Caucasian	Widowed	1	I	2	2
79	Caucasian	Divorced	0	I	2	3
62	Black	Never Married	0	I	3	5
86	Caucasian	Widowed	0	I	2	3

In all 5 cases the nature of the assistance provided included bathing and housework. Three of these clients have shopping done for them and two others receive home delivered meals and use paratransit services.

THE MOST IMPAIRED

Of the 13 subjects designated as 'most impaired' (Group III), all but one live with a family member. Ten are married and 2 live with a daughter. The data show that in each of these cases there is greater reliance on informal support than on formal support. This is documented by counting the number of activities for which assistance is provided by each source of support, as presented in Table 11.

Table 11

Source of assistance provided to those most impaired (Group III)

Total Score ADL/IADL	Household Composition	# Activities for which assisted by informal support	# Activities which assisted by formal support
38	daughter	9	4
41	spouse	8	4
34	spouse	5	3
40	spouse	11	3
40	spouse	4	3
38	spouse	6	2
34	spouse	6	2
34	spouse	6	3
39	spouse	7	1
32	daughter	7	4
38	spouse	11	5
41	spouse	7	3
37	alone	2	8

For the one client in this group who lives alone, the balance is the reverse, with formal support services outweighing the provision of informal supports. This evidence negates our hypothesis that severely impaired elders use more formal support than do less impaired elderly. On the contrary, informal supports are far more extensive for severely impaired elderly living in the community than are formal supports. As previously noted, the presence of a family caregiver is the single most important deterrent to institutionalization. "As long as I can take care of my mother at home, I will. I think I will collapse, but I refuse to." What often sustains the family caregiver is the provision of formal support. In fact, those with the highest support networks

are the most impaired. Equally impaired persons who lack informal supports presumably are institutionalized. It is only the less impaired individual who may be maintained in the community by formal supports alone. We must pay attention to the vital importance of informal support systems.

CAREGIVER CHARACTERISTICS

It is thus pertinent to present a scant overview of some of the characteristics of this group of family caregivers. Of the 14 shared households, one half of the caregivers are men and one half are women. Seven of the caregivers are themselves over the age of 70. Eight are in poor health or disabled. All have limited financial resources and 3 take care of other dependents. Clearly, without the added assistance of formal support services, two people in each of these households would be at serious risk. Table 12 provides us with a synopsis of the situations.

Table 12

Characteristics of the Caregiver Dyad

CLIENT			ETHNICITY	CAREGIVER				
Sex	Age	Level of Impairment (by Group)		Sex	Age	Relation-ship	Health Status	# Activities Assist With
F	74	III	Black	F	31	Daughter	Good	9
F	68	III	Black	M	70	Husband	Good	8
F	70	III	Caucasian	M	75	Husband	Fair	4
M	72	III	Black	F	66	Wife	Good	11
M	67	I	Caucasian	F	59	Ex-wife	Poor	4
F	80	III	Caucasian	M	77	Husband	Poor	4
F	83	III	Caucasian	M	73	Husband	V. Poor	6
F	71	II	Caucasian	M	68	Brother	Good	6
M	76	III	Black	F	74	Wife	Good	6
M	74	III	Caucasian	F	57	Wife	Disabled	6
F	63	III	Caucasian	M	66	Husband	Fair	7
* F	80	III	Caucasian	F	55	Daughter	Disabled	6
F	75	III	Black	M	77	Husband	V. Poor	9
M	71	III	Caucasian	F	70	Wife	Good	7

* just deceased

Practitioners can most effectively design a program of home care for an impaired older client if they consider not only the physical capacity and financial resources available to the older person, but also the physical, psychological and financial strains on the caregiver.

RELATIONSHIP BETWEEN LEVEL OF IMPAIRMENT AND SUPPORT SYSTEMS

In order to determine a measure of association between the extent of impairment and the provision of informal and formal supports a scale was devised to categorize the levels of support being provided. Three categories were created, low, medium, and high, to measure the extent of assistance, that is, the number of tasks for which help was given. The range of assistance provided to subjects by informal supports was from 0 to 11, with a mean of 4.2 tasks being provided per person. The range of assistance from formal supports was from 1 to 8, with a mean of 3.6. Table 13 describes the categorization of formal and informal supports.

Table 13

n = 30

Informal Supports		n	%	Formal Supports		n	%
Low	0 - 2	11	37%	Low	1 - 2	7	23%
Medium	3 - 5	8	27%	Medium	3 - 4	15	50%
High	6+	11	37%	High	5+	8	27%

Using these categories and the Group I, II and III categories to describe the extent of subjects' impairment, a measure of association between these variables was obtained.

Table 14

Measure of association between level of impairment and informal supports

Informal Supports	ADL/IADL Group III (most)	Group II (moderate)	Group I (least)		
High	10	1	0	11	
Medium	2	5	1	8	
Low	1	4	7	11	
	13	10	7	30	Gamma = .88

In examining the strength of the relationship between level of impairment and provision of informal support we get a Gamma value of .88 which indicates that there is a strong positive relationship

between these two variables. The greater the extent of the subject's impairment, the greater is the amount of informal support provided.

Table 15

Measure of association between level of impairment and formal supports

Formal Supports	ADL/IADL Group III (Most)	Group II (Moderate)	Group I (Least)		
High	1	6	1	8	
Medium	8	3	4	15	
Low	4	1	2	7	
	13	10	7	30	Gamma = -.22

A Gamma value of -.22, which was obtained for the relationship between level of impairment and provision of formal supports, indicates that there is a weak negative relationship between the two variables. Contrary to our original hypothesis, the evidence based on data gathered for this study clearly shows that the level of informal support provided is greater, the greater the extent of the subject's impairment.

An additional test was done to try and further establish the relationship between level of impairment and social supports. A table was devised to examine the strength of the relationship between the density of support network (based on the score compiled from visits, telephone calls, confidante and emergency contact), and level of impairment.

Table 16

Density of Support Network with Level of impairment

Density of Support Network	Group III (Most)	Group II (Moderate)	Group I (Least)		
High	4	0	1	5	
Medium	6	6	3	15	
Low	3	4	3	10	
	13	10	7	30	Gamma = .13

With a Gamma value of .13 indicating a relationship that is very weak but in the expected direction, very little can be said about the association between density of social supports and level of impairment. More important is the association between level of impairment and provision of informal supports. Without having asked questions on a subject's mood, morale or satisfaction with social supports, the information gathered on social support networks furnishes us with little more than a count of numbers and frequency of contacts.

DISCUSSION

The hypothesis that a positive relationship exists between a person's level of impairment and reliance on provision of formal supports is negated by the data presented in this study. What has emerged is that formal support services are important to supplement and sustain rather than supplant informal supports. Those elderly who live alone, have the fewest informal supports, and who are being maintained by the provision of formal support services are the least impaired of the group. Beyond a certain level of impairment the provision of formal supports alone is not sufficient to keep the frail elderly at home. The need for formal support is not less for those who are less impaired, but rather their vulnerability for institutionalization comes from a lack of informal supports rather than from the extent of their impairment. It is a well recognized fact that it is the never-married, the widowed, the childless and those with few other relatives who are the inhabitants of nursing homes. The vast majority of patients in nursing homes are chronically impaired elderly who need help with the basic activities of daily living. Most such patients could be cared for at home with paraprofessional help. The difference is not in the level of disability, but the availability of social supports.[20] As has been documented here, with family supports enhanced by formal support services, the severely impaired can and do remain in the community.

However, it has been suggested that social networks may not necessarily be beneficial to well-being because their efforts may exceed their abilities. O'Brien and Wagner[21] raise the possibility that "informal social ties block proper access to useful services

rather than lead to more humane and cheaper alternatives." Certainly there are benefits from informal social supports, but now we are alerted to the danger that there may be limitations to reckon with.

COST EFFECTIVENESS

The Alameda County Homemakers Program is providing 4442 hours of service per year to 30 clients with a fund of $35,000 and in-kind services absorbed the the Family Counseling and Community Services Agency, so that the public cost for maintaining each client is approximately $1106 per year. This compares with an annual cost of $4062 per client, based on data from a recent report to the State legislature which indicated that a savings of approximately $325,000 over a two year period was realized while serving 4000 clients through Medicaid waivers for in-home and community support services. Granted, we do not know the extent of impairment in this latter group, but both programs are designed to serve the impaired elderly who are most at risk for institutionalization.

The family offers almost the sole alternative to solitary or institutional living. Support services such as those provided through the Alameda County Homemakers Program are effective in buttressing the family caregiver's capacity to help the older person and keep him/her at home longer. Clearly the provision of formal support services neither duplicates nor replaces the family.

RECOMMENDATIONS

One of the initial intents of this project was to examine characteristics of the 30 persons then on the waiting list to determine their level of impairment, nature of social supports and how their needs were being met, compared with the 30 persons receiving services. However the nature of the clientele is such that an attempt to maintain such an extensive waiting list proved to be impractical. At the inception of the study only 6 new persons had been added during the prior year. Thus a stagnant list of over 30 names had been maintained over an indefinite period, some referrals having been made more recently than others. A large percentage of recent referrals were coming from a

single source, a particular discharge planner from one of the community hospitals. Sporadic referrals came from such sources as a Senior Center, the Adult Day Health Care program, a Public Health Nurse, a private Doctor, and a private Home Health Care Agency. Although the granting agency stressed outreach to the agency administering the program, without greater movement amongst the subjects being served, or an expanding program, outreach seemed to be an exercise in futility. The point is not that outreach is futile, but rather that funding for the provision of services to more people is necessary. Certainly there is a high-risk population in the community sorely in need of formal support services such as those provided by this program, a unique program to meet the unique needs of low income elderly. As one 77 year old man, caring for an incapacitated wife put it, "I've always taken care of myself. I've been paddling my own canoe all my life. Now I have $33 a month too much income to qualify for MediCal. My neighbor on SSI gets daily service and I get nothing." More crudely put was the same point, made in frustration by another lifelong contributor to society, "I've kissed everyone's ass that I'm going to kiss."

In keeping with the original intent of the study, contact was pursued for each of the names being kept on record, with ultimately 7 interviews being conducted. Generally the level of impairment is so great and the need so imminent that being indefinitely retained on a waiting list hardly meets the urgency of the situation. Of the 30 names on record, 9 were unreachable. Whether these were cases which had improved, deteriorated or were institutionalized will not be known. It was found that 2 patients had died; 2 were now in need of 24 hour care; one had moved in with a daughter; one was managing to pay for some services for the present; 2 had been rehospitalized and were receiving Medicare services; one's condition had improved; 3 others said that they were "managing o.k. now"; 3 were added on to the Program for services and 7 welcomed an interview to assess their current need. A compilation of their demographic data and level of functional impairment very closely matches those characteristics of the population being served. It is not known at what cost or at what level of suffering they are carrying on. As one author states, there is no way of knowing

how many of the impaired elderly in the community actually receive the help they need with personal care and how many simply suffer.[22]

What this program needs is more funding to expand the services and a shorter viable waiting list. Then outreach should be fostered. A review of comparable costs of institutional care for the same population would certainly confirm that the money allocated for this program is being well spent. More is needed. One caregiving woman wrote, upon the death of her spouse who was maintained at home until the end, "The service is wonderful. You have seen me through some trying times. I'm 88 and a little scared of the future but I count my blessings and thank you for all the TLC."

CONCLUSION

The frail elderly who neither want nor need institutional care should have available alternatives to unnecessary institutionalization. Because of the dependency noted in the areas of Instrumental Activities of Daily Living this population does not qualify for formal supports provided under the medical model of subsidized care. The bias of public funding towards nursing home care when supportive community services are often more appropriate has fostered unnecessary institutionalization.[23] Under current funding provisions government programs provide for acute care versus chronic conditions; institutional care versus community-based care; and skilled nursing care versus paraprofessional and informal services. In order for a comprehensive home care system to be developed, Medicare eligibility requirements must be modified.[24] Innovative approaches are further necessary to develop services designed to strengthen the support family caregivers already provide. A recurring theme in the literature addressing policy issues in providing help to older adults is the respective role of the informal support system and the formal support system. This study reaffirms a major theme of the 1981 White House Conference on Aging, and that is, the need to support the roles and functions of the informal network. For these impaired elderly the availability of formal programs to to supplement and support the activities of informal helpers may be crucial in either maintaining an adequate standard of living or in preventing premature institutionalization.

Footnotes

1 Branch, L.G. & Jette, A.M., Elder's Use of Informal Long-Term Care Assistance, The Gerontologist, 1983, pp. 51-56.

2 Alameda County Health Care Services Agency Long Term Care Plan, Executive Summary, February, 1986.

3 Brody, S. et.al. The Family Caring Unit, The Gerontologist, 1983, pp. 558-562.

4 "Medicare", U.S. Senate Hearings, 1979, p. 22.

5 "Long-Term Care", U.S. Congressional Budget Office, 1977.

6 Home and Community-Based Services, Report to the Legislature, 1985

7 Shanas, E., Social Myth as Hypothesis, The Gerontologist, 1979, pp. 3-9.

8 Branch, & Jette, op. cit.

9 Stoller, E.P. & Earl, L.L. Help with Activities of Everyday Life, The Gerontologist, 1983, pp.64-70.

10 Gallo, F., The Effects of Social Support Networks on the Health of Elders, Social Work in Health Care, 1982, pp.65-75.

11 Thoits, P., Conceptual, methodological and theoretical problems in studying social support, Journal Health & Social Behavior, 1982, pp.145-159.

12 Stoller, E.P. & Earl, L.L., op. cit.

13 Chappell, N.L. Social Support and the Receipt of Home Care Services, The Gerontologist, 1985, pp.47-54.

14 Grant funds from the Alameda County Department on Aging, under Title III B Older American Act Funds.

15 O'Brien, J.E. & Wagner, D.L., Help seeking by the frail elderly, Social Work in Health Care, 1982, pp.78-83.

16 VNA Position Paper "Regarding Health Paraprofessionals", San Francisco Home Health Services, S.F. 1985.

17 Report of the Interagency Statistical Committee on Long-Term Care for the Elderly, U.S. Office of Management & Budget, 1980.

18 Ibid.

19 Branch, L.J., & Jette, A.M., op. cit.

20 Brody, S., Poulschock, W., & Masciocchi, A., "The Family Caring Unit: A Major Consideration in Long Term Support System", paper presented at Annual Meeting of the Gerontology Society, 1977.

21 O'Brien, J.E., & Wagner, D.L., op.cit.

22 Crystal, S., America's Old Age Crisis, Public Policy and the Two Worlds of Aging, 1982.

23 Senate Subcommittee on Long Term Care,Nursing Homes in the United States, in Olson, The Political Economy of Aging, 1982, p. 143.

24 Harrington, C., Newcomer, R., Estes, C., Long-Term Care of the Elderly, Public Policy Issues, 1985.

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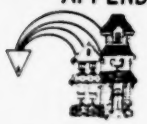
AGENCY ADDRESS

APPENDIX A



MEDISERV HOME CARE SERVICES

INSTRUCTION SHEET

Patient: _____ Age: _____

Diagnosis: _____ Allergies: _____

Impairments: _____ ☐ Speech ☐ Vision ☐ Sensation ☐ Hearing

Physician: _____ Phone Number: _____

Emergency Notification: _____ Phone Number: _____
(family, friend)

HYGIENE:

Bath: ☐ Tub ☐ Shower ☐ Bed ☐ Sponge

Oral Care: _____

Other: _____

SPECIAL INSTRUCTIONS: _____

ELIMINATION:

Bladder: _____

Bowel: _____

Ostomy — Type: _____

ACTIVITES: _____ EQUIPMENT: _____

MEALS: ☐ Diet _____

Prepare: ☐ Breakfast ☐ Lunch ☐ Dinner ☐ Snack ☐ Supplement ☐ Feed ☐ Assist

Other: _____

MEDICATIONS: _____

RESPONSIBLE PARTY: _____

MONITOR: ☐ TPR ☐ BP ☐ Mental Status SPECIAL INSTRUCTIONS:

TREATMENTS: ☐ ROM ☐ Skin SPECIAL INSTRUCTIONS:

HOME MANAGEMENT/HOUSEKEEPING SERVICES:

☐ Mop/Sweep floors ☐ Vacuum ☐ Dust ☐ Clean Bathroom ☐ Transportation

☐ Dishes ☐ Laundry ☐ Iron ☐ Shopping ☐ Clean Kitchen

Other: _____

Prepared by: _____ Title: _____ Date: _____

APPENDIX B

FACE SHEET

_____CV_____R_____Waiting list_____ Date information recorded_____

lient#_____ Date telephoned:_____

AME: _____

DDRESS: _____

HONE NUMBER: Interview appointment_____

EX - F M Rescheduled_____

GE: DATE OF BIRTH: ETHNICITY:

ATE FIRST CALLED:

ATE SERVICE BEGAN: ENDED:

EADMIT: ENDED:

EADMIT: ENDED:

EFERRED BY: RELATIONSHIP:

REFERRAL PHONE #:

IVING SITUATION:

NCOME:

NY OTHER ASSISTANCE IN HOME:

EALTH PROBLEM OR HANDICAP:

OGNITIVE FUNCTIONING: NORMAL _____IMPAIRED_____

HAT KIND OF ASSISTANCE IS NEEDED:	PROVIDED:	HOURS/WEEK:
a) personal care	personal care	
b) housekeeping	housekeeping	
c) shopping	shopping	
d) meal preparation	meal preparation	
e) activity assistance (toilet, transfer, exercise)	activity assistance	
f) companionship	companionship	

OMMENTS:
(for clients, record comments and observations noted during most recent week).

QUESTIONNAIRE

1. Interview # _____

2. Marital Status - Married

   Widowed

   Never Married

   Divorced/separated

3. Ethnicity -

4. Living arrangements -

   1. same house
   2. same city
   3. Bay Area
   4. Outside of Bay Area

5. LIVING CHILDREN Sex Age Location of Residence

   _____ _____

   _____ _____

   _____ _____

   _____ _____

   Education:

6. What are your sources of income? Pension
   Social Security
   SSI
   Savings
   Other

7. What kind of help do you need, or get, to complete your medical claim forms, income tax, etc? Someone helps me
   No one helps me.

   Who helps you? - relative
   friend
   paid help/professional

Self-maintenance and Activities of Daily Living with Social Supports

ADL - I = independent
A = assisted
U = unable

	I	A	U	Spouse	Family	Friend/ Neighbor	Hired Helper	Social Services	Needed but not Receiving	Before services who helped?
Telephone Use										
Ambulation at Home										
Ambulation within walking distance										
Shopping - groceries/clothes										
Meal preparation										
Housework										
Medications										
Money management										
Eating										
Dressing										
Hygiene and Appearance										
Bathing/showering										
Transfer in/out of bed										
Toileting										
Transportation.										

Source: D. Catalano & C. Johnson, Outpatient utilization and latent social needs. Paper presented at the 35th Annual Meeting of the Gerontological Society of America, Boston, 1982

SOCIAL SUPPORTS

Describe a typical day: (Probes - what time get up, what do in the morning, lunch, afternoon, dinner, evenings, what time go to sleep, weekends?)

Do you ever go out?

Who have you seen, talked to on the telephone, had a letter from, during the past week. (v - visit; t - telephone; l - letter)

	Yes	No	N/A
Spouse			
Son			
Daughter			
Sibling			
Relative			
Friend/neighbor			
Formal support (includes home care worker)			

Do you have a close friend? (Is there someone you can talk to when something bothers you, a confidant?)

Is there someone you can call on in an emergency? Yes/No

Who?(relationship)

CLIENT EVALUATION OF SERVICE:

How many hours of service per week are you receiving?

Is this enough time allowed for you?

Is there a need for increasing the time?
If yes, explain:

Is there a need for decreasing the number of hours per week?
If yes, explain:

What kinds of things is the worker doing for you?

Are you satisfied with the housekeeping/homemaker services?

Additional comments:

These are some programs serving older adults in Alameda County.
Have you ever hear of or made use of any?

	Yes Heard of	No Not Heard	Use	Did Use
Linkages				
Paratransit				
Adult Day Health Care				
Social Day Care				
Home Delivered Meals				
Congregate Meals				
Legal Assistance for Seniors				
Senior Companion Program				
Life Line				
Telephone Reassurance				
Weatherization/Energy Services				
Area Agency on Aging				

OBSERVATIONAL - INTERVIEWER EVALUATION

1) Unimpaired 2) Mildly impaired 3) Severely impaired

SENSORY PERCEPTION

		Assistive Devices, Comments
Ambulation		
Speech		
Vision		
Hearing		
Respiration		
Reality Orientation		

PSYCHOLOGICAL STATUS - Subjective Impression

1) Not at all impaired 2) A little impaired 3) Moderately impaired

4) Quite impaired 5) Extremely impaired

		Observations, Comments
Appearance		
Motor coordination		
Energy Level		
Communication		
Cognition (organization of ideas)		
Attention Span		
Fidgety		

Self-maintenance and Activities of Daily Living with Social Supports

ADL - I = independent
A = assisted
U = unable

	I	A	U	Spouse	Family	Friend/ Neighbor	Hired Helper	Social Services	Needed but not Receiving	Before services who helped?
Telephone Use										
Ambulation at Home										
Ambulation within walking distance										
Shopping - groceries/clothes										
Meal preparation										
Housework										
Medications										
Money management										
Eating										
Dressing										
Hygiene and Appearance										
Bathing/showering										
Transfer in/out of bed										
Toileting										
Transportation,										

Source: D. Catalano & C. Johnson, Outpatient utilization and latent social needs. Paper presented at the 35th Annual Meeting of the Gerontological Society of America, Boston, 1982

APPENDIX C